Complete Summary

GUIDELINE TITLE

Practice parameters for the assessment and treatment of children, adolescents, and adults with autism and other pervasive developmental disorders.

BIBLIOGRAPHIC SOURCE(S)

American Academy of Child and Adolescent Psychiatry. Practice parameters for the assessment and treatment of children, adolescents, and adults with autism and other pervasive developmental disorders. American Academy of Child and Adolescent Psychiatry Working Group on Quality Issues. J Am Acad Child Adolesc Psychiatry 1999 Dec;38(12 Suppl):55S-76S. [173 references]

COMPLETE SUMMARY CONTENT

SCOPE

DISEASE/CONDITION(S)

1. Autistic disorder
2. Pervasive developmental disorders:
    - Rett's Disorder
    - Childhood Disintegrative Disorder (CDD)
    - Asperger's Disorder
    - Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)/Atypical Autism

GUIDELINE CATEGORY

Diagnosis
Evaluation
Treatment

CLINICAL SPECIALTY

Pediatrics
Psychiatry

INTENDED USERS

Allied Health Personnel
Physicians
Psychologists/Non-physician Behavioral Health Clinicians
Social Workers

GUIDELINE OBJECTIVE(S)

To present guidelines for clinicians who care for children with autism and other pervasive developmental disorders.

TARGET POPULATION

Children with autism or related pervasive developmental disorders

INTERVENTIONS AND PRACTICES CONSIDERED

Diagnosis: Complete psychiatric assessment:

- Historical information including pregnancy, neonatal, and developmental history; medical history; family and psychosocial factors; intervention history.
- Psychiatric examination of the child; behavior observation in various settings; overall developmental level; specific problem behaviors.
- Medical assessment, including audiological and visual examination, neurological assessment; laboratory studies; consultative services by geneticists, pediatric neurologists and other medical professionals.
- Psychological assessment, including developmental/intelligence testing, adaptive skills, neuropsychological and/or achievement testing.
- Speech-Language-Communication assessments.
- Occupational and physical therapy assessments.

Treatment

Psychosocial treatment

- Educational services, including special education, some forms of behavior modification and other services.
- Parent training (e.g., in behavior modification techniques) and referral to parent/sibling support groups.

Pharmacological and related interventions

- Medications for associated symptoms, including the neuroleptics, selective serotonin reuptake inhibitors, tricyclic antidepressants, lithium and mood stabilizers, and anxiolytics.

MAJOR OUTCOMES CONSIDERED

Not stated

METHODOLOGY

METHODS USED TO COLLECT/SELECT EVIDENCE

Searches of Electronic Databases

DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

Multiple comprehensive literature searches were conducted using Medline and Psychological Abstracts. Although the focus was on papers published in the past decade older sources were, of necessity, included as relevant. Over 20 recent books were consulted. A bibliography of over 3,500 references was developed for this review. The review process was facilitated by the various reviews of the literature and data reanalyses developed for DSM-IV and published in the DSM-IV source books. In addition, the recent National Institute of Health State of the Science Conference on Autism and the associated research reports provided an extremely helpful overview of research findings. For purposes of the present review, an emphasis was placed, when possible, on recent scientifically rigorous studies, rather than single case reports or uncontrolled research. In some instances, review articles and chapters were particularly helpful in providing either meta-analyses of available data or summaries of current knowledge. As noted subsequently, in some areas it is clear that research is lacking.

NUMBER OF SOURCE DOCUMENTS

Over 3,500

METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Not stated

RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

Not stated

METHODS USED TO ANALYZE THE EVIDENCE

Review

DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

Not applicable

METHODS USED TO FORMULATE THE RECOMMENDATIONS

Expert Consensus

DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS

Clinical consensus was determined through extensive review by the members of the Work Group on Quality Issues, child and adolescent psychiatry consultants with expertise in the content area, the entire Academy membership, and the Academy Assembly and Council.

RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Not applicable

COST ANALYSIS

A formal cost analysis was not performed and published cost analyses were not reviewed.

METHOD OF GUIDELINE VALIDATION

Internal Peer Review

DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

Twelve individuals are acknowledged by name for reviewing the practice parameters. These parameters were made available to the entire Academy membership for review in September, 1998 and were approved by the Academy Council on June 27, 1999.

RECOMMENDATIONS

MAJOR RECOMMENDATIONS

Autism and other pervasive developmental disorders are conditions of onset in the first years of life which disrupt various developmental processes. The diverse expression of these disorders both across and within individuals presents particular challenges for clinical assessment and treatment. Individuals with these conditions may present for evaluation and treatment at any point in the life cycle. Clinicians must be aware of the tremendous range in syndrome expression and the complexities of developmental change. The variety, intensity, and comprehensiveness of services needed by individuals with these conditions as well as the participation of professionals from various disciplines require the efforts of some professional to coordinate and advocate for the child. In this regard it is important that the clinician encourage and welcome the participation of the parents and, as appropriate, other family members in the assessment process; support of the parents and family as well as the affected child is an important goal for the clinician.

The Evaluation Process

A complete psychiatric assessment is indicated. Aspects of the assessment will vary depending on the child's age, history, and previous evaluations.

Historical Information

In taking the history the clinician should be particularly aware of features important in differential diagnosis such as the nature of social relatedness in the first years of life, difficulties in the development of language and communication skills, and unusual environmental responses. In many cases parents may be asked to complete rating scales or symptom checklists specific to autism and related conditions:

- Pregnancy, Neonatal, and Developmental History. This includes a review of the pregnancy, labor, and delivery and early neonatal course. A developmental history should be taken and should include review of communicative and motor milestones. Aspects of the onset or recognition should be reviewed, e.g., when were parents first concerned about the child and why were they concerned, were any aspects of the child's early development unusual, and so forth.
- Medical history. Should include discussion of possible seizures, sensory deficits such as hearing or visual impairment, or other medical conditions including signs of specific syndromes such as the Fragile-X syndrome, and history of the use of behavior modifying medications. The family history should be reviewed for the presence of other developmental disorders or autism. The review of current and past psychotropic medications should include a discussion of dose and the child's behavioral response, along with adverse as well as positive effects of the agent. The impact of other medications on behavioral status should also be reviewed.
- Family and psychosocial factors. The interviewer should be sensitive to the family situation as well as to family supports and stresses. It is important that the efforts of various specialists and consultants be well coordinated and that at least one care provider assumes an overall role as coordinator and liaison with schools and other providers of intervention.
- Intervention history. Includes review of response to any educational program as well as response to any behavioral interventions. Materials that may be reviewed include reports of previous evaluations for educational and other services, information based on standard rating scales and symptom checklists, any narrative reports of teachers or care providers, and review of individual educational programs. The examiner should obtain an overall sense of the quality, intensity and appropriateness of the program and the child's response to it.

Psychiatric Examination of the Child

- Observational settings. Given the potentially adverse impact of new and/or unstructured environments on the child's behavior, the clinician should be prepared to observe the child in both more and less structured settings such as the home or school. The clinician should be alert to factors in the environment which impact positively or negatively on the child, e.g., an overstimulating school setting for a child who is overly sensitive to extraneous stimuli. Clarification about how representative the child's behavior is can be helpful. Observation of the child in interaction with parents and siblings can

also provide important information on the child, on the levels of stress experienced by the family in response to the child's symptoms, and on the effectiveness of parental interventions. Several sessions are usually needed.

- Overall developmental level. Characteristic symptoms in the areas of social interaction, communication/play, restricted and unusual interests and behaviors, and any unusual features (e.g., hand-washing stereotypes) should be evaluated relative to overall developmental level. This should include observation of level of language and communication skills exhibited by the child and any unusual strengths, weaknesses, or special interests that may impact on programming.
- Specific problem behaviors. The clinician should note the presence of specific problem behaviors which interfere with programming and require behavioral or pharmacological intervention, for example, aggression, self injury, or stereotype.

Medical Assessment

- Goals of assessment. Physical examination of the child is concerned with a search for treatable medical conditions, for conditions that sometimes produce symptoms suggestive of pervasive developmental disorder (PDD), and for conditions with important implications for the family, e.g., inherited medical conditions such as Fragile X syndrome or tuberous sclerosis.
- Initial and Subsequent Medical Assessment. A medical history and physical examination should be obtained. The physician should be aware of medical conditions frequently associated with autism, e.g., relative to screening for inherited disorders such as Fragile X and tuberous sclerosis, which may guide the examination and laboratory studies. As part of routine medical care standard information (immunization history, history of allergies or unusual responses to medication) and routine laboratory studies should be obtained. The latter should include lead levels as the high rate of pica in this group of children increases the risk for lead intoxication.
- Audiological and Visual Examinations. Concerns about possible deafness are a typical initial presenting complaint. Frequent ear infections may be reported or, in some cases, chronic ear infections may be late in being recognized because of the child's language delay. Although behavioral audiometry is often initially attempted brain stem auditory evoked response auditory should be conducted if there is any question that prior audiological assessment has not been definitive. Similarly, concerns regarding vision should prompt thorough assessment.
- Neurological Assessment. Given the frequency of seizure disorders in this population, observation of the child for symptoms suggestive of seizures and careful review of neurological status with parents are indicated. Symptoms suggestive of seizure disorder should prompt EEG and/or neurological consultation.
- Laboratory Studies. There is no specific laboratory test for autism. Specific studies to search for associated conditions are indicated based on history and clinical presentation. Fragile X testing is typically indicated given the apparent association of this condition with autism as is Wood´s lamp examination for tuberous sclerosis. A DNA test for Fragile X syndrome is now available. Depending on the history and examination additional tests may be indicated. The presence of dysmorphic features or other specific findings may suggest

obtaining genetic screening for inherited metabolic disorders or chromosome analysis.
- Consultative Services. Evaluations from various other professionals may be indicated given the history and examination. These may include evaluations by geneticists, pediatric neurologists, and other medical professionals. For individuals with Rett's disorder, the services of orthopedists and respiratory therapists may be needed.

Psychological Assessment

- Developmental/Intelligence Testing. Assessments of the child's cognitive ability are indicated to establish overall levels of function and, in many states, eligibility for services from some agencies. Whenever possible, separate estimates of verbal and nonverbal (performance) IQ should be obtained.
- Adaptive Skills. Assessment of adaptive skills is essential to document the presence of any associated mental retardation and in helping to establish priorities for treatment planning.
- Other assessments. Neuropsychological and/or achievement testing may be needed, depending upon the clinical context.

Speech-Language-Communication Assessments

- Vocabulary. Measures of single word vocabulary (receptive and expressive) should be obtained whenever possible.
- Language Skills. Actual use of language (receptive and expressive) should be assessed, over and above the level of single word vocabulary.
- Articulation and Oral-Motor skills. Difficulties with articulation or specific oral-motor difficulties should be assessed as appropriate.
- Pragmatic Skills. The social use of language-communication skills is often an area of great difficulty for individuals with autism and related disorders. During the course of a formal assessment the clinician should evaluate the child's capacities for use of whatever level of communication skills he/she has in relation to the social context.

Occupational and Physical Therapy Assessments

Assessments may be indicated, particularly if there is some degree of sensory hyper or hyposensitivity or difficulties in motor development.

Family and Parental Support

To the extent possible it is important to involve parents and, as appropriate, other family members, in the process of assessment. This helps to set the stage for a long-term collaborative relationship and also helps parents become better informed advocates for their child. Various parent and family support groups may provide important sources of information and support to parents (see Appendix 1 in the guideline document).

Differential Diagnosis

The differential diagnosis includes consideration of the various pervasive developmental disorders, mental retardation not associated with PDD, specific developmental disorders (e.g., of language), and early onset psychosis (e.g., schizophrenia) among others. Specific guidelines for diagnosis of the various pervasive developmental disorders are provided in DSM-IV: autistic disorder, childhood disintegrative disorder, Rett's disorder, Asperger's disorder, and PDD-NOS (atypical autism):

- In autistic disorder the apparent onset of the condition is almost always within the first years of life. Parents may initially be concerned that the child is deaf although they also report unusual sensitivities to the nonsocial environment. Language is typically significantly delayed or absent. Unusual behaviors, (e.g., stereotyped movements) are common, particularly after about age 3 years.
- In childhood disintegrative disorder, there is a prolonged period of normal development followed by a marked regression in multiple areas and the development of many autistic-like features.
- In Rett's disorder, very early growth and development is normal but is followed by a deceleration in head growth, development of marked mental retardation, and unusual hand washing stereotypes and other features.
- In Asperger's disorder, early development (including both cognition and language development) is apparently normal, the child often has unusual interests which are pursued with great intensity. Social deficits become more prominent as the child enters preschool and is exposed to peers.
- In PDD-NOS (atypical autism), criteria for one of the other PDDs are not met but the child has problems in social interaction and other areas consistent with a diagnosis of PDD.

The differential diagnosis of autism and other pervasive developmental disorders also includes consideration of various other developmental and psychiatric conditions:

- Mental retardation or borderline intelligence often coexists with pervasive developmental disorder. Usually in mental retardation, social and communicative skills are at levels expected given the child's overall development. Individuals with severe and profound mental retardation may exhibit various autistic-like features, particularly stereotyped movements. Mental retardation is not usually observed in association with Asperger's disorder.
- Specific developmental disorders, particularly language-related disorders, may sometimes mimic autism and related conditions. Usually in the language disorders, the primary deficits are in the area of language/communication, social skills are relatively preserved, and the unusual restricted interests and behaviors associated with autism are not present.
- Rarely schizophrenia has its onset in childhood. Usually there is a previous history of normal or near normal development with the onset of characteristic hallucinations and delusions typical of schizophrenia appearing later in development.
- Selective mutism sometimes is confused with autism and related conditions. In selective mutism the child's ability to speak in some situations is preserved, but the child is mute in other situations. The history and presentation are quite different from autism and related conditions. Although

it is the case that children with autism are often mute, their mutism is not selective in nature.

- Social anxiety disorder may sometimes be confused with autism or other pervasive developmental disorder (particularly PDD-NOS) but with the exception of social anxiety the other criteria for autism would not be present.
- Stereotypic movement disorder is characterized by motor mannerisms (stereotypes) and the presence of mental retardation. A diagnosis of stereotypic movement disorder is not made if the child meets criteria for one of the pervasive developmental disorders.
- Occasionally a dementia has its onset in childhood. In some cases the child will fulfill criteria for childhood disintegrative disorder, in which case that diagnosis as well as the specific medical diagnosis causing the dementia would be made. The typical pattern in dementia of childhood onset is one of progressive deterioration in functioning.
- Some children with obsessive compulsive-disorder present with unusual interests and behaviors. Usually, however, social skills are preserved, as are language/communication skills.
- In schizoid personality disorder, the child is relatively isolated but has the ability to relate normally in some contexts.
- Avoidant personality disorder is characterized by anxiety in dealing with social situations.
- In reactive attachment disorder, there usually is a history of a marked or very severe neglect. The social deficits of reactive attachment disorder tend to remit dramatically in response to a more appropriate environment.

A multi-axial, developmentally based approach to differential diagnosis is very useful. Specific behaviors can then be viewed in the context of intellectual, communicative, and other abilities. When standardized assessments, (e.g., of intelligence or language), are used it is important that they be selected to be appropriate to the individual. Measures of adaptive skills are readily obtained and help to guide intervention programs.

The developmental stage and level of the individual are important in assessment and treatment. For infants and very young children, there should be increased awareness of the complexities of diagnosis. For example, not all of the features of autism may be present before age 3. Asperger's disorder is rarely diagnosed before age 3. The clinician should also be aware that marked neglect can lead to problems in social interaction which initially might suggest autism or PDD.

Treatment

The Treatment Plan

Planning for the individual's program of services is essential in insuring consistency and efficacy of intervention. This planning should include parents and family members as well as school staff and other professionals. In treatment planning some elements are always or almost always required (e.g., establishing goals for educational intervention for school age children) while others are relevant depending on the clinical context and available evidence regarding efficacy (e.g., in indications for and use of pharmacological interventions). Treatments proposed should be based on solid, empirical evidence. Treatment planning should include a realistic assessment of available resources as well as

characteristics of the child which may impact (positively or negatively) on the intervention program.

The treatment plan should address:

- Establishing goals for educational intervention.
- Establishing target symptoms for intervention.
- Prioritizing target symptoms/co-morbid conditions.
- Monitoring multiple domains of functioning (including behavioral adjustment, adaptive skills, academic skills, social-communicative skills, and social interaction with family members and peers).
- Monitoring medication for efficacy and side effects, as appropriate.

Psychosocial Treatments

- Educational services (including special education, some forms of behavior modification, and other services) are the central and integral aspect of the treatment of autism in children and adolescents. Federal law 94-142 mandates the provision of an appropriate educational plan for all children in the U.S. and provides specific rights to parents. As part of this educational program, ancillary services are often required. These include speech-language therapy, occupational therapy and physical therapy. Sustained and continuous programming is more effective than episodic programming. The option for summer programming may be needed since children with these conditions often regress in the absence of such services. Professionals should be prepared to consult and collaborate with teachers and other school personnel.
- Psychosocial interventions include parent training (e.g., in behavior modification techniques) and referral to parent/sibling support groups. In some cases parental counseling may be appropriate or, for the affected individual, social skills training and/or highly structured individual counseling or psychotherapy may be indicated particularly for older and higher functioning individuals.
- In some cases parents will seek additional ancillary treatments outside the school setting. It is important that providers of such services coordinate their work with that of the other providers.

Pharmacological and Related Interventions

- Medications may be useful for symptoms which interfere with participation in educational interventions or are a source of impairment or distress to the individual. The medications are not specific to autism and do not treat core symptoms of the disorder and their potential side effects should be carefully considered. The neuroleptics, selective serotonin reuptake inhibitors, tricyclic antidepressants, lithium and mood stabilizers, and anxiolytics have been used in these patients with varying degrees of success.
- Dietary and other alternative treatments are not clearly established as being efficacious. Families should be helped to make informed decisions about their use of alternative treatments. Treatments which pose some risk to the child and family should be actively discouraged.

Follow-Up Assessments and Ongoing Treatment

- Usually services are needed at different points in the child's development for various lengths of time. Coordination of services and family support are important aspects of ongoing care. The nature and intensity of such contact depend on the clinical situation and needs of the individual. More frequent contact is needed for individuals who receive psychotropic medication or who exhibit behaviors which pose a danger to the individual or others or which interfere with the provision of an appropriate educational intervention program.

Developmental Issues in Assessment and Treatment

Educational services are less frequently available for infants and young children, less than three years, but should be utilized whenever possible. While early intervention undoubtedly is very helpful, important questions remain to be addressed, e.g., what features of the treatment are most important and what characteristics of the child are associated with greatest improvement. If medications are used in this age group, considerable caution should be exercised and the child monitored very closely.

For school-aged children the eligibility for supportive services such as respite care may be important. This may depend upon establishing eligibility for services through state departments of mental retardation.

For adolescents with autism and related conditions, there should be more emphasis on vocational and prevocational skills as well as on adaptive skills. The latter are prerequisites for independent and semi-independent living. The clinician should help to identify areas of strength for vocational planning. It is important to note that during adolescence some children make major gains while slightly more exhibit significant developmental losses. Emerging sexuality may present other issues. The adolescent may also be more capable of participating directly in treatment and treatment planning. Co-morbid conditions, such as depression in individuals with Asperger's disorder, may first be seen in adolescence.

Among adults with autism and related conditions, the identification of community resources and support in planning for long-term care is critical. In many states individuals with PDD as adults are not eligible for services unless they are also eligible on the basis of associated mental retardation. These services may include provision of supported employment and supported residential living arrangements. Individuals without eligibility for state-supported services are often most in need of care. Services provided may depend upon having eligibility established for Department of Mental Retardation support. The latter may include provision of supported employment and supported residential living arrangements.

CLINICAL ALGORITHM(S)

None provided

EVIDENCE SUPPORTING THE RECOMMENDATIONS

TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The type of supporting evidence for each recommendation is not stated. In general, the parameters are based on evaluation of the scientific literature and relevant clinical consensus.

BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

POTENTIAL BENEFITS

Accurate psychiatric diagnosis and appropriate treatment for children, adolescents and adults with autism and other pervasive developmental disorders.

POTENTIAL HARMS

Not stated

QUALIFYING STATEMENTS

QUALIFYING STATEMENTS

Practice parameters are strategies for patient management, developed to assist clinicians in psychiatric decision-making. These parameters are not intended to define the standard of care; nor should they be deemed inclusive of all proper methods of care or exclusive of other methods of care directed at obtaining the desired results. The ultimate judgment regarding the care of a particular patient must be made by the clinician in light of all the circumstances presented by the patient and his or her family, the diagnostic and treatment options available, and available resources. Given inevitable changes in scientific information and technology, these parameters will be reviewed periodically and updated when appropriate.

IMPLEMENTATION OF THE GUIDELINE

DESCRIPTION OF IMPLEMENTATION STRATEGY

An implementation strategy was not provided.

INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

IOM CARE NEED

Living with Illness

IOM DOMAIN

Effectiveness
Patient-centeredness

IDENTIFYING INFORMATION AND AVAILABILITY

BIBLIOGRAPHIC SOURCE(S)

American Academy of Child and Adolescent Psychiatry. Practice parameters for the assessment and treatment of children, adolescents, and adults with autism and other pervasive developmental disorders. American Academy of Child and Adolescent Psychiatry Working Group on Quality Issues. J Am Acad Child Adolesc Psychiatry 1999 Dec;38(12 Suppl):55S-76S. [173 references]

ADAPTATION

Not applicable: The guideline was not adapted from another source.

DATE RELEASED

1999 Jun 27

GUIDELINE DEVELOPER(S)

American Academy of Child and Adolescent Psychiatry - Medical Specialty Society

SOURCE(S) OF FUNDING

Not stated

GUIDELINE COMMITTEE

Not stated

COMPOSITION OF GROUP THAT AUTHORED THE GUIDELINE

Principal Authors: Fred Volkmar, MD; Ed Cook, Jr., MD; John Pomeroy, MD; George Realmuto, MD; Peter Tanguay, MD.

Work Group on Quality Issues: William Bernet, MD (Chair); John E. Dunne (former Chair); Maureen Adair, MD; Valerie Arnold, MD; Joe Beitchman, MD; R. Scott Benson, MD; Oscar Bukstein, MD; Joan Kinlan, MD; Jon McClellan, MD; David Rue, MD; Jon Shaw, MD.

AACAP Staff: Elizabeth Sloan, LPC; Kristin Kroeger.

FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

As a matter of policy, some of the authors to these practice parameters are in active clinical practice and may have received income related to treatments discussed in these parameters. Some authors may be involved primarily in research or other academic endeavors and also may have received income related to treatments discussed in these parameters. To minimize the potential for these parameters to contain biased recommendations due to conflict of interest, the

parameters were reviewed extensively by Work Group members, consultants, and Academy members; authors and reviewers were asked to base their recommendations on an objective evaluation of the available evidence; and authors and reviewers who believed that they might have a conflict of interest that would bias, or appear to bias, their work on these parameters were asked to notify the Academy.

GUIDELINE STATUS

This is the current release of the guideline.

An update is not in progress at this time.

GUIDELINE AVAILABILITY

Electronic copies: Available (to members only) from the American Academy of Adolescent and Child Psychiatry (AACAP) Web site.

Print copies: Available from AACAP, Communications Dept., 3615 Wisconsin Ave, NW, Washington, DC 20016. Additional information can be obtained through the AACAP Publication Catalog for Parameters.

AVAILABILITY OF COMPANION DOCUMENTS

The following is available:

- American Adademy of Child and Adolescent Psychiatry (AACAP). Summary of the practice parameters for the assessment and treatment of children, adolescents, and adults with autism and other pervasive developmental disorders. J Am Acad Child Adolesc Psychiatry. 1999 Dec;38(12):1611-6.

Print copies: Available from AACAP, Communications Dept., 3615 Wisconsin Ave, NW, Washington, DC 20016. Additional information can be obtained through the AACAP Publication Catalog for Parameters.

PATIENT RESOURCES

None available

NGC STATUS

This summary was completed by ECRI on February 28, 2000. The information was verified by the guideline developer on October 18, 2000.

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